#### S.B. No. 92 (Autism Services)

This legislation was introduced on May 12, 2015. As of May 28, it awaited action by the Senate Education Committee. The Committee is scheduled to hear the bill on June 3. The bill is earmarked with an "incomplete" fiscal note.

The bill revamps the current statutory framework for the Delaware Autism Program (DAP) initially adopted in the early 1980s. I have the following observations.

First, the bill does not update the statute covering supportive services and residential units for children with autism. See attached 14 Del.C. §3123. Consistent with the attached articles from 2010, there was a significant controversy over the residential program. I do not believe the differences among stakeholders were ever finally resolved. It may be preferable to incorporate revisions to §3123 into S.B. No. 92.

Second, S.B. No. 92 ostensibly uses different terminology to refer to the same director. Compare S.B. No. 93 (line 93) reference to "Statewide Director of the Delaware Autism Program" with S.B. No. 92 (line 43) reference to "Director of Autism Educational Services". It would be preferable to adopt the same terminology.

Third, in line 46, I recommend substituting "with" for "from". In the same line the reference to "(see subsection (d)" merits revision since a) the Peer Review Committee is mentioned in subsection "(g)", not subsection "(d)"; and b) the reference is superfluous and does not conform to the legislative drafting guide.

Fourth, periods are omitted at the end of lines 46, 60, 84, and 97.

Fifth, lines 49-60 are rather prescriptive in defining the required experience of the Director. One could posit that they are overly prescriptive. For example, someone who "inherited" and implemented a structured professional development program and a performance management plan over a period of years, but did not develop the initial plan, would not qualify. It may be preferable to include some of the standards in the certification contemplated at lines 61-62.

Sixth, there are many references to assisting districts (e.g. lines 69, 81, 88) and some funding is derived from districts (lines 98-99). However, charter schools might also benefit from training and technical assistance opportunities. The sponsors may wish to consider whether to limit training and technical assistance to districts. In other contexts (e.g. lines 73-74), the Director is authorized to assist "state departments" and act as a liaison to agencies serving adults.

Seventh, there may be some "duplication" in training responsibilities between the Director and the Network established by S.B. No. 92. <u>Compare</u> S.B. No. 92 (lines 68-69, 79-83) with S.B. No. 93 (lines 63-65, 79-81, and 90-91). I recognize that S.B. No. 93 (lines 92-93) contemplates collaboration between the Network and Director. Given different funding streams, this may work in practice or it may result in disagreements over responsibilities.

Eighth, lines 85-86 authorize funding for at least 1 training specialist per 100 students with an educational classification of ASD. It appears the specialists would be employed by the Director rather than districts and that the director could "cash in" the specialist funds for contractual services rather than hiring specialists (lines 105-106). The synopsis predicts there will be 15 specialists hired based on the funding formula. The sponsors could consider an alternate model in which the districts employed the specialists. This would promote better integration among the balance of district special education staff and participation as a district representative on IEP teams. Some safeguards would have to be put in place to prevent supplanting of speech-language pathologists and other specialist positions. Since there are 19 districts, the formula could also be adjusted to ensure each district earns at least 1 specialist. Otherwise, the approach in the bill may result in "enriched" staffing within the DAP which places district-operated, local programs at a staffing disadvantage.

Ninth, lines 113-131 represent a revised version of current 14 <u>Del.C</u>. §1332(d). The retention of the Peer Review Committee and Statewide Monitoring Review Board (SMRB) merit reconsideration. Consider the following:

- A. Consistent with the attachments relating to the 1984 legislation creating the Committee and Board, the impetus was the desire to provide safeguards in the <u>residential</u> program as juxtaposed to day programs.
- B. Lines 119-122 require the Board to review annually both the eligibility and program of every district student with a classification of ASD. The synopsis to the attached 1980 legislation is informative. It recites that there were only 32 students statewide with an ASD classification. Now there are hundreds. It not realistic to have a single board review the eligibility and educational program of all of these students every year.
- C. It is not appropriate to have some central board determining classification of students within districts.
- D. Lines 125-126 establish the authority of the Board to resolve disputes between agencies. Districts can be determined to be "out of compliance" (lines 128) and forced to develop a "corrective action plan" (line 130) This scheme is inappropriate. The current Department of Education regulation limits the authority of the Board to an "advisory capacity". See 14 DE Admin Code 929.2.2.3.6. I suspect the DOE has not followed the statutory mandate in recognition of its inconsistency with the overall IDEA procedural safeguards system.

E. Having a single board rule on the appropriateness of programming will stifle innovation. At one time, ABA therapy was considered untested and controversial. Now it is mainstream. Consistent with the attached July 7, 2014 CMS Information Bulletin, innovation in ASD programming is thriving: "While much of the current national discussion focuses on one particular treatment modality called Applied Behavioral Analysis (ABA), there are other recognized and emerging treatment modalities for children with ASD, including those described in the ASD Services, Final Report on Environmental Scan...".

I recommend sharing the above observations with policymakers.

Attachments

E:legis/sb93separate

#### § 3123 Supportive services and residential programs.

- (a) Any school district administering a program for children with autism may provide from its own personnel or contract with another state agency or a private service provider if necessary for appropriate supportive services, including, but not limited to, respite care, physical, art and music education, psychological services, language and speech therapy, physical and occupational therapy. The supportive services to be provided shall be based upon a program for each child as approved by the Department of Education; provided, that the State Board may review any objection to the Department's decision. The school district designated by the Department with State Board approval as the administering agency for a statewide program for autistic pupils shall annually submit in its budget a request for funds for such services.
- (b) Community-based residential units for children with autism may be operated by a school district designated and approved by the Department with State Board approval as the administering agency for a statewide program for autistic pupils. When the school district operates a community-based residential program, that program shall meet the following minimum standards:
  - (1) Pre-puberty and post-puberty children shall be housed separately. In no case shall a child under age 12 be housed with a child over age 16 except as approved by the Human Rights and Peer Review committees of the statewide autistic program.
  - (2) Residential units shall be provided at the rate of 1 residential unit for each 4 residential pupils except that a maximum of 5 pupils may be housed in 1 residential unit. Pupils housed for the purpose of respite care, additionally defined to mean a period not to exceed 12 months, shall not be counted with respect to this provision. At no time shall the total number of pupils exceed 6 including respite placements.
  - (3) Residential teacher coordinators shall be provided for a period of 12 months per year at the rate of 3 full-time equivalent teacher coordinators per residential unit.
  - (4) Residential child care specialists shall be provided for a period of 12 months per year at the rate of 6 full-time equivalent residential child care specialists per residential unit. The Department with the approval of the State Board of Education shall determine the necessary educational requirements for the residential child care specialists.

61 Del. Laws, c. 190, §§ 5, 8; 64 Del. Laws, c. 381, §§ 1, 2; 71 Del. Laws, c. 180, § 151; 77 Del. Laws, c. 424, § 15.;



# Using group homes causes rift

# Director says residential service out of district's scope

By MIKE CHALMERS • The News Journal • August 16, 2010

Lia Park has **autism**, and by age 15, she still couldn't speak, couldn't use the bathroom and had a habit of severely gouging her own eye.

"Somebody had to always be with her," said her mother, Patrice Park. "She was dependent on us for all of her care."

Lia's frustrated parents turned to a special service offered through the Delaware Autism Program, where she was enrolled as a student. For two weeks, Lia lived in a Newark group home, where staffers successfully taught her to use the toilet.

"It was just an awesome experience," Patrice Park said. "It was part of her education program. It wasn't baby-sitting or putting her away somewhere."

The lessons worked so well that her parents began sending her to the home frequently to work on other behaviors. For the past six years, Lia regularly spent as many as five nights a week at one of DAP's three homes.

That's a problem, said DAP director Vincent Winterling.

The service isn't held to the same training, licensing and accreditation standards as another group home, he said. And the Christina School District, which hosts DAP in New Castle County, isn't supposed to run a residential treatment program, he said.

"What in God's name is the school district doing providing residential treatment?" Winterling said.

"We're not accountable, we're not licensed," he said. "Nobody really knows what the program is. I'm looking at it thinking, 'Come on, this is crazy.' "

Winterling wants to eliminate overnight stays, currently offered to only seven or eight of DAP's more than 700 children statewide. But Delaware parents and autism advocates are resisting.

"If it's not working, let's fix it," said Kim Herbert, of Pike Creek, whose 7-year-old twin sons have autism.

"My boys might need it someday, so I don't want to see it go anywhere," said Herbert, president of DAP's parent advisory council. "If we get rid of the residential home, there's no getting it back."

The Christina School Board has not made any decisions on Winterling's recommendations, said Wendy Lapham, spokeswoman for Christina School District.

Such residential treatment programs are falling out of favor among most autism advocates and researchers, said Jeff Sell, vice president of advocacy and public policy for the Autism Society, a national advocacy group. The trend is now toward offering services in the community or a family's home because it is less expensive and more effective, he said.

Residential programs "are what everybody wants to avoid," said Sell, who has twin 16-year-old sons with autism.

Services now offered by DAP's homes could be



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provided by behavioral experts who come to a family's home, Sell said.

Winterling said the homes could still be used to teach life skills to autistic children, just not overnight. He has proposed the service be phased out over the next year.

Fifteen students, from ages 12 to 21, currently receive the service at the homes. About half of them, including Lia Park, are leaving this month because they have turned 21, Winterling said.

"For the 12-year-olds, we can't be here for nine more years," Winterling said. "Something else is needed in your family's life, and the school district can't be it."

Winterling called the current program "a risk-management nightmare" because it doesn't meet the industry's standards for group homes. That leaves the program, its staff, the school district and the state open to legal blame if a student is injured or killed in an accident at one of the homes, he said.

"This is no longer the 30-year-ago world where you just gave your child and said, 'Take care of my kid,' " Winterling said. "We live in a litigious society."

Also, the three homes are in Newark, making the service impractical for families living downstate, he said.

The service should continue until a better one is in place, said Theda Ellis, executive director of Autism Delaware, an advocacy organization aimed at helping families affected by the disorder.

"What concerns me is closing this program without having an alternative," Ellis said. "We need some time to figure out who can do this."

Autism is a complex neurological disorder that affects the way a person communicates and interacts with others. It affects about one out of every 110 U. S. children, according to the Centers for Disease Control and Prevention.

Autistic children pose challenges for their families, parents said, but their issues are compounded when they reach adolescence.

Deanna Principe, of New Castle, wants the service to be available if her autistic daughter, now 11, needs

"It has turned into something it wasn't meant to be," Principe said. "But there's nothing else in place right now. So if that goes away, these families are left with nothing."

DAP, the nation's only statewide public school program for children with autism, started the residential service in 1985 when Marie-Anne Aghazadian and other parents pressed for an alternative to expensive, out-of-state group homes for children with difficult behavioral issues.

"We were a small group of parents who were able to win over a few legislators," Aghazadian said.

Aghazadian's son, Stefan, now 39, spent time in the homes to shower, dress himself and make basic m icrowave meals. He now lives in an adult group home.

"It allowed us to have a more typical family life," she said. "If he hadn't learned them in that setting, he would have never learned them."

Families with severely autistic children might have to accept that their child needs a full-time group home, Winterling said. There are no such homes for children in Delaware, so that means placing them in Pennsylvania, New Jersey or another state, he said.

The homes cost \$150,000 to \$200,000 a year for



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each child, Winterling said. The state would have to pick up much of that cost.

"Is it a high cost? Yes, it is," Winterling said. "But we've got to have the discussion about what we're doing with these kids. Nobody's going to be put on the street."

Ellis said Delaware does not have money to put into residential services, and in this political and economic climate, state residents and legislators are unlikely to raise taxes to pay for the services.

"I don't disagree with Vince, but I don't think it's going to happen," Ellis said.

Stacey O'Rourke, of Pike Creek, wants the service to remain in place if her 5-year-old daughter and twin 3-year-old girls, all with autism, need it.

But only if it is safe, she said.

"To have a school manage a residential facility is a lot," O'Rourke said.

Contact Mike Chalmers at 324-2790 or mchalmers@delawareonline.com.



Purchase this Photo

Patrice Park helps daughter Lia put on her shoes. For six years Lia Park spent as many as five nights a week at one of the Delaware Autism Program's three homes — and that's a problet DAP's director said. (The News Journal/GINGER WALL)



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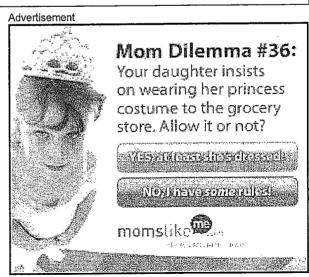
Purchase this Photo

Sammy Principe, 11, swims at Camp Manito in Wilmington on Thursday. Sammy's mom, Deanna, wants the DAP service to remain. "If that goes away, these families are left with nothing," she said. (The News Journal/JENNIFER CORBETT)



Purchase this Photo

Deanna Principe helps daughter Sammy, 11, put on her backpar while picking her up at the Variety Autism Camp held at Camp Manito in Wilmington on Thursday. (The News Journal/JENNIF CORBETT)



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John Sweeney Editorial Page Editor **QUOTE OF THE DAY** 

"We pick a side and go with it, and if we're wrong, we're wrong."

Sussex County developer Preston Schell of Schell Bros. on political endorsements by businesses

**DUR VIEW** 

# Schools must do better job of helping autistic students

Unanswered questions about the legality of a residential program for autistic students being hosted by the Christina School District can no longer be ignored. Until they are resolved, the

QUESTIONS OF an COMPLIANCE

school district and the Delaware Autism Program

have a moral and legal obligation to see that the special needs children enrolled in it receive the appropriate standard of care.

There is no doubt that the special services offered through DAP are a saving grace for parents of students with this complex neurological disorder.

With 1 out of every 110 U.S. children diagnosed, many are so severely affected that they require care of highly skilled health care and behavioral specialists. DAP serves more than 700 children.

The organization has contributed to the state's positive reputation for services to children, who in most cases are taught separately from the majority student population.

That's why it's as concerning that the severest critic of the current circumstances comes from DAP Director Vincent Winterling.

"We're not accountable, we're not licensed," Winterling said. "Nobody really knows what the program is. I'm looking at it thinking, 'Come on, this is crazy."

What a ringing indictment of the very "risk-management nightmare" Winterling predicts.

While parents can make a case for positive outcomes on their children's development in the residential setting, priority one should be to make sure it's safe and medically compliant.

# Delaware does not have run these homes, but we do believe there must be up on autistic student not really the issue. The issue is will. istrict must not g

Last Monday's article, "Using group homes causes rift," on the Delaware Autism Program (DAP) group homes hit on many

that the Legislature, the key points. It should be recognized

parents that locally School Disagreed years trictdelaware THEDA M. Ellis voice

the school day, teaching specific educational goals The program extends most cost-effective way to address the needs of these challenged students.

as the number of students goals during the day in ent training so students in That training never fully materialized as initially envisioned and has subsequently been reduced school or at home. Initially, the DAP also provided parthe residential program fully transition back home. would be able to successinćreased. and

ment four years ago that it ling that the group homes tified. Christina signed a would do that - it could and should be licensed and ceragree with Dr. Wintermemorandum of agreecomplete should ago run group homes were the

DAP group home staff consists of certified teachprocess

been able to learn these

to children who have not

residential programs, thus they should have even ers and paraprofessionals who are typically better paid than staff of typical more skills than a standard residential program.

abilities, including Chris-tina's Sterck School for the school-run residential servthere is a rich history of ices for other unique disment that residential services are not an appropriate public education service, Concerning the argu-Deaf.

acutes.Southerfact that the aged by public education is The reason for group homes for children with but the need is no less DAP group homes are manautism may be different

an in-state program for Sending children out of Autism Delaware is not is not cost-efficient. the professional expertise state is not the answer and nor the funding to do this. provides. To do it in the We have 10-25 children who are going to need the additional support that residential programming

children with autism who require a residential component.

Theda M. Ellis is executive director of Autism Delaware.

saying that the DAP must

home would be ideal, but



## Future unclear for Delaware Autism Program homes

#### Legislators, school board say they're out of loop

By NICHOLE DOBO • The News Journal • October 1, 2010

Nearly a month after the Delaware Autism Program's director publicly called for the closing of a residential program, some elected officials say they've been shut out of the decision-making process.

Officials from the state Department of Education hosted a meeting with several state agencies this week but declined to allow Christina school board members to take part. And two state legislators, one Republican and one Democratic, say there's been a troubling lack of information about issues surrounding DAP's three residential homes.

"Apparently they have circled the wagons," said state Rep. William A. Oberle, R-Beechers Lot, "and it's very difficult to figure out what is going on."

The homes serve as a temporary residential facility for a handful of children from across the state who need intensive help to reach education goals. The program's new director, Vincent Winterling, has said staff is not properly trained and there are liability

Winterling, who declined to be interviewed for this story, said in an August interview with The News Journal that the homes should be closed and children in need of these services should be sent elsewhere. This would mean these children would be sent to neighboring states, with Delaware absorbing costs of \$150,000 to \$200,000 per child a year.

"Is it a high cost? Yes, it is," Winterling said in the earlier interview. "But we've got to have the discussion about what we're doing with these kids. Nobody's going to be put on the street."

The 25-year-old program is utilized and funded by

school districts statewide, but the operating power rests with the Christina School District. Most everyone agrees that changes need to be made at the homes, but it's not clear how to go about doing it. There appears to be a fundamental disagreement between the state and the Christina School Board in regards to who has the right to steer the decisionmaking process.

There's a fear that the state will come up with its own plan, cutting out the elected board and other key stakeholders, said Rep. Quinton Johnson. D-Middletown. The state needs to work with elected officials and the public, rather than making a decision, then pretending to take suggestions from others. Johnson said.

Christina school board member Elizabeth Scheinberg agrees, saying the school board and state should work collaboratively.

"If you are going to bring all the parties to the table, you ought to bring all the parties to the table," she

The elected officials weren't invited to the meeting about the problems facing the homes held Tuesday.

The purpose of the meeting was to "find a solution to use the community residences" in a way that will benefit families, said Martha Toomey, the state Department of Education's director of special education. She intends to find a way to keep the program open.

That could mean contracting out services to private



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providers but keeping the children in state, she said.

Oberle -- who said he is against closing the homes -- has been waiting more than two months for detailed information about exactly what's wrong with the homes.

He has not yet received a response from Secretary of Education Lillian Lowery, and he's concerned that key decisions will be made before others are brought into the fold.

"This is the first time I feel like I've been stonewalled on an issue from her," Oberle said. "And I never thought I'd live long enough to say that."

Lowery explained that she did not communicate with Oberle because she had nothing to share.

It was a mistake not to get back to him, she said, apologizing that it happened.

State officials intend to host a public forum, Lowery said, but they first needed an initial meeting that only included some agency heads so that the issues could be outlined.

No date for the public meeting has been set, Lowery said.

"We have never done this before," Lowery said.
"Before we get people stirred up, let's see what we have here."

Parent Kim Herbert, who is president of the DAP parent group and the mother of twin boys who have autism, said she believes Winterling makes valid points about problems in the homes.

The homes are in such a poor condition that she cried after seeing them, she said.

"Please, don't close it," Herbert said. "Lets figure out what we can do with it."

Officials need to work to keep the homes open because there are parents who need help with real issues beyond their abilities, advocates say.

"We have children with autism who definitely need a residential component to their education," said Theda Ellis, executive director of the Autism Society of Delaware. "We just don't have a lot of alternatives. Private school is very expensive."

Contact Nichole Dobo at 324-2281 or ndobo@delawareonline.com.



Rep. William Oberle said legislators haven't



Education Secretary Lillian Lowery said

#### On the Web

- \*\* Delaware Department of Education
- Christina School District
- \* Delaware General Assembly



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# Delaware Society for Children and Adults with Autism

P.O. Box 9666 • Newark, DE 19714-9666

Reasons why the Delaware Society for Children and Adults with Autism is supporting Senate Substitute #3 for Senate Bill #89.

- The Autistic Children who are presently being housed at the Governor Bacon Health Center will have to be moved by 1985 as that facility will close.
- Through private funds, a residential-educational facility has been made available to the Autistic Program to house the above mentioned children in the community.
- If such a facility becomes operational, the following mechanisms ought to be in place:
  - A peer review committee.
  - A human rights committee
  - An Autistic monitoring board.
- With these committees in place in conjunction with an educational residential community based facility and a job training-placement person, children that are now being serviced out of State could be brought back at a great saving to the State.
- The Delaware Society for Children and Adults with Autism feels very strongly that such community based educational-residential facilities should be planned very carefully without ignoring the rights of the children or the other members of the community.

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DELAWARE STATE SENATE

132ND GENERAL ASSEMBLY

SENATE SUBSTITUTE NO. 3

FOR

SENATE BILL NO. 89

AS AMENDED BY

#### · SENATE AMENDMENT NO. 1

AN ACT TO AMEND CHAPTER 31; TITLE 14; DELAWARE CODE, AS IT RELATES TO STANDARDS FOR RESIDENTIAL SERVICES FOR AUTISTIC PERSONS AND JOB TRAINING AND PLACEMENT SERVICES FOR AUTISTIC PERSONS.

BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF DELAWARE:

Section 1. Amend Section 3123, Chapter 31, Title 44, Delaware Code by redesignating the existing paragraph as subparagraph "(a)", inserting after the words "but not limited to" the words "respite care," and striking the last sentence of said subparagraph and inserting in lieu thereof the sentence, "The school district designated by the State Board of Education as the administering agency for a statewide program for autistic pupils shall annually submit in its budget a request for funds for such services."

- Section 2. Amend Section 3123, Chapter 31, Title 14, Delaware Code by adding after the first paragraph the following:
  - "(b) Community-based residential units for autistic children may be operated by a school district designated and approved by the State Board of Education as the administering agency for a statewide program for autistic pupils. When the school district operates a community based residential program, that program shall meet the following minimum standards:
    - (1) Pre-puberty and post-puberty children shall be housed separately. In no case shall a child under age twelve (12) be housed with a child over age sixteen (16) except as approved by the Human Rights and Peer Review Committees of the Statewide Autistic program.

- (2) Residential units shall be provided at the rate of one residential unit for each four residential pupils except that a maximum of five pupils may be housed in one residential unit. Pupils housed for the purpose of respite care, additionally defined to mean a period not to exceed twelve (12) months, shall not be counted with respect to this provision. At no time shall the total number of pupils exceed six (6) including respite placements.
- (3) Residential teacher coordinators shall be provided for a period of twelve (12) months per year at the rate of three (3) full-time equivalent teacher coordinators per residential unit.
- (4) Residential child care specialists shall be provided for a period of twelve (12) months per year at the rate of six full-time equivalent residential child care specialists per residential unit. The State Board of Education shall determine the necessary educational requirements for the residential child care specialists.

Section 3. Amend §1332, Chapter 13, Title 14, of the Delaware Code by adding thereto a new §(f) to read as follows:

"(f) The State Board of Education shall adopt such rules and regulations to establish and provide for Parent Advisory Committees, a Peer Review Committee, a Human Rights Committee, and appropriate liasons with the Department of Health and Social Services. The State Board of Education shall adopt such rules and regulations to establish and provide for an Autistic Program Monitoring Board, to be composed of no less than seven (7) members and which shall include one (1) non-voting public representative nominated annually by the Delaware Society for Children and Adults with Autism and who does not have a child enrolled in the autistic program. The Statewide Autistic Monitoring Review Board shall review at least annually the identification, evaluation, and educational program and placement of each autistic pupil and the provision for a free appropriate public education to such pupils. Disputes within or between districts or agencies shall be resolved by this Board. Procedural safeguards guaranteed to autistic pupils, their parents or guardians and to local school districts or agencies shall not be diminished by this provision."

# 54NOPSIS TO HB 93 (1980)

1	in §1321 (e) (14) (a). Teachers shall be employed at the rat
2	of the number of pupil units as of the last day of September
3	of a regular school year. A fraction greater than one-half
4	shall be considered a unit.
5	Section 7. Unless otherwise appropriated no additional funds
6	shall be appropriated for carrying out the provisions of this Act during
7	the fiscal year beginning July 1, 1980.
8	Section 8. Except as set forth in Section 7 of this Act, the
	provisions of this Act shall take effect July 1, 1980.

#### SYNOPSIS

Provision for the statewide autistic program as a contingency has proved to be most troublesome to budget and to coordinate. This bill sets forth the special school core staff ratios required but undefined in 14 Del.C., §3123.

This bill follows exactly the language of House Bill No. 875 introduced for the purpose of clarifying legislative intent with regard to the employment of specialized personnel, sharing of personnel, and aggregating units across district lines.

With regard to pre-kindergarten age children, in the previous three years, a total of 3 children were identified. The parent/child trainer position is for all children 0-21 and is presently funded with P. L. 89-313 funds.

With regard to authorization for pupil days beyond 217 days, programming and respite care services have already been budgeted through a federal developmental disability grant.

The very low incidence of autistic persons is reflected by the fact that 32 children were served statewide during the current fiscal year. Provision for 41 children statewide has been made in the budget for the coming fiscal year.

Correcting the under estimate for the residential unit through an amendment to the Omnibus Amendment Bill will allow the funding of all the above staff and services with existing federal, state, and local funds.

DEPARTMENT OF HEALTH & HUMAN SERVICES Centers for Medicare & Medicaid Services 7500 Security Boulevard, Mail Stop S2-26-12 Baltimore, Maryland 21244-1850



#### **CMCS Informational Bulletin**

DATE:

July 7, 2014

FROM:

Cindy Mann, Director

Center for Medicaid and CHIP Services

SUBJECT: Clarification of Medicaid Coverage of Services to Children with Autism

In response to increased interest and activity with respect to services available to children with autism spectrum disorder (ASD), CMS is providing information on approaches available under the federal Medicaid program for providing services to eligible individuals with ASD.

#### Background

Autism spectrum disorder is a developmental disability that can cause significant social, communication and behavioral challenges. A diagnosis of ASD now includes several conditions that used to be diagnosed separately: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger syndrome. These conditions are now all called autism spectrum disorder. Currently, the Center for Disease Control and Prevention (CDC) estimates that approximately 1 in 68 children has been identified with ASD. <sup>1</sup>



Treatments for children with ASD can improve physical and mental development. Generally these treatments can be categorized in four categories: 1) behavioral and communication approaches; 2) dietary approaches; 3) medications; and 4) complementary and alternative medicine. While much of the current national discussion focuses on one particular treatment modality called Applied Behavioral Analysis (ABA), there are other recognized and emerging treatment modalities for children with ASD, including those described in the ASD Services, Final Report on Environmental Scan (see link below)<sup>3</sup>. This bulletin provides information related to services available to individuals with ASD through the federal Medicaid program.

The federal Medicaid program may reimburse for services to address ASD through a variety of authorities. Services can be reimbursed through section 1905(a) of the Social Security Act (the Act), section 1915(i) state plan Home and Community-Based Services, section 1915(c) Home

<sup>&</sup>lt;sup>1</sup> http://www.cdc.gov/ncbddd/autism/facts.html

http://www.cdc.gov/ncbddd/autism/treatment.html

http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Downloads/Autism-Spectrum-Disorders.pdf

#### Page 2-CMCS Informational Bulletin

and Community-Based Services (HCBS) waiver programs and section 1115 research and demonstration programs.

#### State Plan Authorities

Under the Medicaid state plan, services to address ASD may be covered under several different section 1905(a) benefit categories. Those categories include: section 1905(a)(6) - services of other licensed practitioners; section 1905(a)(13)(c) - preventive services; and section 1905(a)(10) - therapy services. States electing these services may need to update the Medicaid state plan in order to ensure federal financial participation (FFP) is available for expenditures for these services. In addition, for children, as discussed below, states must cover services that could otherwise be covered at state option under these categories consistent with the provisions at 1905(a)(4)(B) for Early and Periodic Screening, Diagnostic and Treatment services (EPSDT). Below is information on these coverage categories for services to address ASD. Under these section 1905(a) benefit categories all other state Medicaid plan requirements such state-wideness and comparability must also be met.

#### Other Licensed Practitioner Services

Other Licensed Practitioner services (OLP) services, defined at 42 CFR 440.60, are "medical or remedial care or services, other than physicians' services, provided by licensed practitioners within the scope of practice as defined under State law." If a state licenses practitioners who furnish services to address ASD, the state may elect to cover those providers under this section of their state plan even if the providers are not covered under other sections of the plan (e.g., physical therapist, occupational therapist, etc.). A state would need to submit a state plan amendment (SPA) to add the new licensed provider to their Medicaid plan. The SPA must describe the provider's qualifications and include a reimbursement methodology for paying the provider.

In addition, services that are furnished by non-licensed practitioners under the supervision of a licensed practitioner could be covered under the OLP benefit if the criteria below are met:

- Services are furnished directly by non-licensed practitioners who work under the supervision of the licensed practitioners;
- The licensed provider is able to furnish the service being provided;
- The state's Scope of Practice Act for the licensed practitioners specifically allows the licensed practitioners to supervise the non-licensed practitioners who furnish the service;
- The state's Scope of Practice Act also requires the licensed practitioners to assume professional responsibility for the patient and the service furnished by the unlicensed practitioner under their supervision; and
- The licensed practitioners bill for the service;

#### Preventive Services

Preventive Services, defined at 42 CFR 440.130(c) are "services recommended by a physician or other licensed practitioner of the healing arts within the scope of his practice under state law to—

- (1) Prevent disease, disability, and other health conditions or their progression;
- (2) Prolong life; and
- (3) Promote physical and mental health and efficiency"

A regulatory change that took effect January 1, 2014, permits coverage of preventive services furnished by non-licensed practitioners who meet the qualifications set by the state, to furnish services under this state plan benefit as long at the services are recommended by a physician or other licensed practitioner. Under the preventive services benefit, in the state plan, the state must 1) list the services to be provided to ensure that services meet the definition of preventive services as stated in section 4385 of the State Medicaid Manual (including the requirement for the service to involve direct patient care); 2) identify the type(s) of non-licensed practitioners who may furnish the services; and 3) include a summary of the state's provider qualifications that make these practitioners qualified to furnish the services, including any required education, training, experience, credentialing, supervision, oversight and/ or registration.

Therapy Services

Physical therapy, occupational therapy and services for individuals with speech, hearing and language disorders, may be covered under the Medicaid therapies benefit at 42 CFR 440.110. Physical and occupational therapy must be prescribed by a physician or other licensed practitioner of the healing arts within the scope of his/her practice under state law and provided to a beneficiary by or under the direction of a qualified therapist. Services for individuals with speech, hearing and language disorders mean diagnostic, screening, preventive or corrective services provided by or under the direction of a speech pathologist or audiologist, for which a patient is referred by a physician or other licensed practitioner of the healing arts within the scope of his or her practice under state law.

States would need to include an assurance in the state plan that the state furnishes the therapy in accordance with 42 CFR 440.110. States would also need to describe the supervisory arrangements if a practitioner is furnishing the therapy under the direction of a qualified therapist. Finally, for audiology services, the state plan must reflect the supervision requirements as set forth at 42 CFR 440.110(c)(3).

#### Section 1915(i) of the Social Security Act

States can offer a variety of services under a section 1915(i) state plan Home and Community-Based Services (HCBS) benefit. The benefit may be targeted to one or more specific populations including individuals with ASD and can provide services and supports above and beyond those included in section 1905(a). Participants must meet state-defined criteria based on need and typically receive a combination of acute-care medical services (like dental services, skilled nursing services) and other long-term services such as respite care, supported employment, habilitative supports, and environmental modifications.

#### Other Medicaid Authorities

There are several other Medicaid authorities that may be used to provide services to address ASD. Below is a discussion of each of those authorities:

#### Section 1915 (c) of the Social Security Act

The section 1915(c) Home and Community-Based Services waiver program allows states to provide a combination of medical services and long-term services and supports. Services include

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but are not limited to adult day health services, habilitation (both day and residential), and respite care. States can also propose "other" types of services that may assist in diverting and/or transitioning individuals from institutional settings into their homes and community. Participants must meet an institutional level of care but are served in the community. Section 1915(c) waiver programs also require that services be furnished in home and community-based settings. For individuals under the age of 21 who are eligible for EPSDT services, an HCBS waiver could provide services and supports for ASD that are above and beyond services listed in section 1905(a), such as respite care. Additionally, for individuals who are receiving state plan benefits as part of EPSDT that are not available to adults under the state plan, waiver services may be used to help these individuals transition into adulthood and not lose valuable necessary services and supports.

#### Section 1115 Research and Demonstration Waiver

Section 1115 of the Act provides the Secretary of the Department of Health and Human Services broad authority to authorize experimental, pilot, or demonstration programs that promote the objectives of the Medicaid program. Flexibility under section 1115 is sufficiently broad to allow States to test substantially new ideas, including benefit design or delivery system reform, of policy merit. The Secretary can approve an 1115 demonstration for up to five years, and states may submit extension requests to continue the program for additional periods of time. Demonstrations must be "budget neutral" over the life of the program, meaning they cannot be expected to cost the Federal government more than it would cost without the demonstration.

#### **EPSDT Benefit Requirements**

Section 1905(r) of the Act defines the EPSDT benefit to include a comprehensive array of preventive, diagnostic, and treatment services for low-income infants, children and adolescents under age 21. States are required to arrange for and cover for individuals eligible for the EPSDT benefit any Medicaid coverable service listed in section 1905(a) of the Act that is determined to be medically necessary to correct or ameliorate any physical or behavioral conditions. The EPSDT benefit is more robust than the Medicaid benefit package required for adults and is designed to assure that children receive early detection and preventive care, in addition to medically necessary treatment services, so that health problems are averted or diagnosed and treated as early as possible. All children, including children with ASD, must receive EPSDT screenings designed to identify health and developmental issues, including ASD, as early as possible. Good clinical practice requires ruling out any additional medical issues and not assuming that a behavioral manifestation is always attributable to the ASD. EPSDT also requires medically necessary diagnostic and treatment services. When a screening examination indicates the need for further evaluation of a child's health, the child should be appropriately referred for diagnosis and treatment without delay. Ultimately, the goal of EPSDT is to assure that children get the health care they need, when they need it - the right care to the right child at the right time in the right setting.

The role of states is to make sure all covered services are available as well as to assure that families of enrolled children, including children with ASD, are aware of and have access to a broad range of services to meet the individual child's needs; that is, all services that can be covered under section 1905(a), including licensed practitioners' services; speech, occupational,

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and physical therapies; physician services; private duty nursing; personal care services; home health, medical equipment and supplies; rehabilitative services; and vision, hearing, and dental services.

If a service, supply or equipment that has been determined to be medically necessary for a child is not listed as covered (for adults) in a state's Medicaid State Plan, the state will nonetheless need to arrange for and cover it for the child as long as the service or supply is included within the categories of mandatory and optional services listed in section 1905(a) of the Social Security Act. This longstanding coverage design is intended to ensure a comprehensive, high-quality health care benefit for eligible individuals under age 21, including for those with ASD, based on individual determinations of medical necessity.

#### Implications for Existing Section 1915(c), Section 1915 (i) and Section 1115 Programs

In states with existing 1915(c) waivers that provide services to address ASD, this 1905(a) policy clarification may impact on an individual's eligibility for the waiver. Waiver services are separated into two categories: waiver services and extended state plan services. Extended state plan services related to section 1905(a) services are not available to individuals under the age of 21 (individuals eligible for EPSDT) because of the expectation that EPSDT will meet the individual's needs. There are therefore a limited number of services that can be provided to this age group under 1915 (c) waivers, primarily respite, and/or environmental/vehicle modifications.

For states that currently provide waiver services to individuals under age 21 to address ASD, the ability to provide services under the 1905(a) state plan may have the effect of making these individuals ineligible for the waiver unless another waiver service is provided. This implication is especially important for individuals with ASD who may not otherwise be eligible for Medicaid absent the (c) waiver. States need to ensure that these individuals are receiving a waiver service, not coverable under section 1905(a), to ensure that they do not lose access to all Medicaid services by losing waiver eligibility. Individuals age 21 and older may continue to receive services to address ASD through the waiver if a state does not elect to provide these services to adults under its Medicaid state plan.

The same issues arise for children under the 1915(i) authority, which allows for services above and beyond section 1905(a) to be provided under the state plan. CMS is available to provide technical assistance to states that currently have approved waivers or state plans that may be impacted by this clarification. Similarly, states with existing 1115 demonstrations authorizing reimbursement for services provided to children with autism should contact CMS to ensure that EPSDT requirements are met.

We hope this information is helpful. If you have questions please send them to AutismServicesQuestions@cms.hhs.gov.